



Influence of the metropolitan environment on end-of-life decisions: A population-based study of end-of-life decision-making in the Brussels metropolitan region and non-metropolitan Flanders

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ABSTRACT

Research is beginning to show differences between end-of-life care in metropolitan and non-metropolitan areas. Using population-based post-mortem surveys this article compares medical end-of-life decisions in the Brussels metropolitan area and non-metropolitan Flanders (Belgium). In Brussels, administering lethal drugs without an explicit patient request occurred more often, intensification of symptom alleviation and non-treatment decisions less often, and end-of-life treatment was more often aimed at cure or life prolongation, than in non-metropolitan Flanders. This paper argues that these differences in end-of-life decisions are related to characteristics of the metropolitan environment and hence may also apply in other metropolitan regions worldwide. Specific approaches to end-of-life decisions in metropolitan areas need to be considered.

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1. Background

Research is beginning to show several differences between end-of-life care in metropolitan and non-metropolitan areas (Gessert et al., 2006a, 2006b; Gessert and Calkins 2001; Houttekier et al., 2010; Hughes, 2005; Lin et al., 2007; Murphy and Price, 1998). However, no research has thus far examined differences in medical end-of-life decisions, i.e. physicians' decisions about care at the end of life that potentially influence the remaining lifetime, between metropolitan and non-metropolitan areas. Medical end-of-life decisions are becoming an increasingly important issue in medicine and public health within the context of growing tension between medical-therapeutic possibilities on the one hand and demands for more patient-centered and comfort-oriented approaches on the other (Danis et al., 1996; Earle et al., 2004; Prendergast et al., 1998; Seale, 2000; The SUPPORT Principal Investigators, 1995). Dying in

Belgium, as in many other developed countries, is increasingly a matter of old age and increasingly typified by a slow degenerative dying process (Corr, 1998). Currently, about half of population dying in Belgium are older than 80; an increasing number are dying from chronic diseases in general, and neurological diseases in particular (Wancata et al., 2003). These trends have created situations in which it is often necessary to make decisions impacting the remaining lifetime, but in which there is also ample time for various end-of-life decisions to be discussed and made. In many terminally ill patients decisions need to be made which set limits to life-support in favor of comfort and dignity even if they hasten or do not postpone death. Such decisions may imply the withholding or withdrawing of life-sustaining treatments, the intensifying of pain and symptom control with high-dose drugs, and, in rare cases, intentional termination of life by means of a lethal dose of drugs (Bilsen et al., 2007; Prendergast et al., 1998; Sprung et al., 2003; van der Heide et al., 2007). Additionally, patients can be deeply sedated until death, often in combination with the withdrawal of food and fluids, as a last resort to counter symptoms that cannot otherwise be relieved (Rietjens et al., 2008; Seale, 2009). The increasing importance of these medical end-of-life decisions in developed countries is not only apparent from their prevalence in patients with different pathologies and in

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different care settings (Bilsen et al., 2004, 2007, 2006, 2009; Bosshard et al., 2005; Cohen et al., 2007; Deliëns et al., 2000; Lofmark et al., 2008; Miccinesi et al., 2006; Prendergast et al., 1998; Rietjens et al., 2007; Seale, 2006; Sprung et al., 2003; van der Heide et al., 2003, 2007), but also from the ensuing ethical and legal debate. Some countries have laws regulating non-treatment decisions and the stepping-up of doses of drugs aimed at pain and symptom alleviation which may also hasten death as a side effect (Burgermeister, 2004; Di Bartolomeo, 2009). A few have even legalized physician-assisted dying by means of lethal drugs, while others are debating decriminalization (Collier, 2009; Finlay et al., 2006; Joffe, 2006). Physician-assisted suicide is legally performed in Switzerland since 1990 (Bosshard et al., 2002; Giroud et al., 1999), and has been legal in Oregon (US) since 1997 (Ganzini et al., 2000), the Netherlands since 2002 (Deliëns and van der Wal, 2003), Washington State since 2008 (Steinbrook, 2008), Luxemburg since March 2009 (Di Bartolomeo, 2009). Legalization is in process in Montana. Euthanasia, defined as the administering of life-ending drugs at the patient's explicit request, is legal in three countries: the Netherlands and Belgium since 2002 (Deliëns and van der Wal 2003), and Luxemburg since March 2009 (Di Bartolomeo 2009).

All collected data on medical end-of-life decisions for Belgium have so far been limited to Flanders (Bilsen et al., 2009); empirical data for the autonomous metropolitan region of Brussels are lacking. There are, however, a number of reasons why studying the specific situation in the Brussels region is particularly relevant. Besides evidence of specific difficulties in organizing good and accessible end-of-life care in urban populations (Hughes, 2005; Murphy and Price, 1998), and of rural–urban differences in end-of-life care (Gessert et al., 2006a, 2006b; Gessert and Calkins, 2001; Houttekier et al., 2010; Lin et al., 2007), a number of demographic, social, and health care provision aspects typical of metropolitan areas feed the assumption that a metropolitan region such as Brussels faces specific challenges to the optimizing of circumstances at the end of life. Compared to those living in the rest of Belgium, people in metropolitan Brussels are more often very old (in 2007, 0.72% of the population in Brussels versus 0.57% of the rest of Belgium were 90 or above) and living alone (the odds of living alone are significantly higher in all age groups in Brussels compared with the rest of Belgium). There is more social fragmentation, resulting in less informal care and fewer social contacts and support networks (Brussels Health and Social Observatory, 2006; Deboosere et al., 2009). On the other hand, the older – though not the younger – residents of Brussels seem to be more highly educated than their Flemish counterparts, making them potentially more self-determined as patients (Deboosere et al., 2009). There are also certain peculiarities involving the organization and use of care in the Brussels metropolitan region that are likely to impact on end-of-life care. As the region acts as a center of service provision to the surrounding area, there is a concentration of institutional care and in particular of large academic hospitals, resulting in many hospital deaths (Houttekier et al., 2009). While the general practitioner (GP) has a gatekeeper's role in access to palliative care in Belgium, residents of Brussels are less likely to have a regular GP and more likely to consult specialists directly than are their counterparts in the rest of Belgium (Belgian Scientific Institute of Public Health Department of Epidemiology, 2006). Also, provision of compassionate leave or other possibilities facilitating palliative care at home are not used as often (Houttekier et al., 2009). There seems to be a more intra-mural focus on end-of-life care compared to non-metropolitan Flanders (Houttekier et al., 2009). Considering all these aspects, one might expect a less favorable situation in the Brussels region regarding timely planning and communication of end-of-life decisions, less

involvement of family members in the decision-making process, and differences in the care provided at the end of life.

While a great deal of attention has been paid to different aspects of urban health, neither research nor policy has thus far concentrated on aspects typical of metropolitan regions that may go together with issues of end-of-life decision-making. The urban environment is said to influence every aspect of health and well-being, including healthcare provision (Galea et al., 2005); it can be expected that the metropolitan environment influences end-of-life decision-making as well. This study, therefore, examines the incidence and characteristics of medical end-of-life decisions in the Brussels metropolitan region for 2007 via a population-based death certificate study, and compares these data with those obtained for non-metropolitan Flanders in a similar study in 2007. By comparing medical end-of-life decisions in metropolitan Brussels and non-metropolitan Flanders and by discussing possible reasons for these differences, this study will provide insight into how the metropolitan environment influences medical end-of-life decisions.

2. Methods

2.1. Study design

The study reports findings from post-mortem questionnaires sent out to physicians attending a representative sample of deaths in Flanders and Brussels, asking them to report on the end-of-life decisions they made in those deaths. Separate death certificate studies were conducted in Flanders, the Flemish-speaking part of Belgium with about six million inhabitants and approximately 55,000 deaths per year, and in Brussels, the bilingual autonomous capital region of Belgium with slightly more than one million inhabitants and approximately 10,000 deaths per year. A random sample of deaths was drawn by the Flemish and Brussels official central administration authorities for death certificates. The Flanders sample was drawn between 1 June 2007 and 30 November 2007 and was divided into four strata based on the underlying cause of death as indicated on the death certificate and the estimated corresponding likelihood of an end-of-life decision having been made (as derived from the data of the Flemish 2001 study on end-of-life decision-making (van der Heide et al., 2003)). Stratum one contained all deaths where an end-of-life decision was certain (i.e. euthanasia indicated as the immediate cause of death); stratum two contained all deaths from neoplasms (ICD-10 codes: C, D00–D48), where a medical assistance in dying was probable; stratum three contained all deaths from causes where this was possible (ICD-10 codes: E, F, G, J, K, N); and stratum four contained all other deaths where this was improbable. In stratum one all deaths were retained in the sample, in stratum two 50% of the deaths, in stratum three 25%, and in stratum four 12.5%. The Brussels sample was drawn from deaths occurring between 1 June 2007 and 30 September 2007. Due to the lower number of deaths compared with Flanders, no stratification was made and a larger sample fraction was used. Of the original Flemish study sample, all deaths in the metropolitan city of Antwerp (the only metropolitan city in Flanders (Houttekier et al., 2010)) were discarded, leaving only deaths from non-metropolitan regions in Flanders. This resulted in a sample of 6244 deaths, which is about 13% of all deaths in 2007. In Brussels 1961 deaths were sampled, which is 60% of all deaths in the sampling period and about 18% of all deaths in 2007.

Every physician certifying the death certificates in both samples was sent a five-page questionnaire for a maximum of five cases, with at most three reminders in cases of non-response. A lawyer acted as intermediary between responding physicians,

researchers, and the administration authorities for death certificates in the mailing procedure to guarantee that completed questionnaires could never be linked to a particular decedent or physician. This lawyer also anonymously linked the coded decedent information from the death certificates received from the administration authorities to the corresponding completed questionnaires received from the physicians and further anonymized the databases. After the data collection a one-page questionnaire was mailed to all non-responding physicians, asking for their reasons for not participating. The study design, sampling, and mailing procedure are described in detail elsewhere (Chambaere et al., 2008). Positive recommendations for the anonymity procedure and study protocols were received from the Ethical Review Boards of the University Hospitals of the Vrije Universiteit Brussel and Ghent University, from the Belgian National Disciplinary Board of Physicians and the Belgian Federal Privacy Commission.

2.2. Questionnaire

The questionnaire used was largely based on the one devised in the Netherlands (van der Maas et al., 1991) and used in previous studies in Flanders (Deliens et al., 2000; van der Heide et al., 2003) and in other countries (Seale, 2009; van der Heide et al., 2003, 2007). It first asked whether death had been sudden and unexpected and whether the attending physician's first contact with the patient had been after death. If neither of these questions were answered affirmatively (and hence end-of-life decision-making prior to death was not precluded) the physician was asked whether he or she had withheld or withdrawn medical treatment taking into account or explicitly intending the shortening of the patient's life, had intensified the alleviation of pain and other symptoms taking into account or co-intending the possible shortening of life, or had administered, supplied, or prescribed drugs with the explicit intention of hastening death. If the latter was the case, the act was classified as euthanasia only if it was done at the explicit request of the patient. If these drugs had not been administered at the explicit request of the patient, this act was classified as 'administering life-ending drugs without explicit request'. If more than one end-of-life decision was made, the one with the most explicit life-shortening intention was considered the most important, and if there was more than one act with a similar life-shortening intention, the administering of drugs was regarded as prevailing over the withholding or withdrawal of treatment. These key questions were followed by questions about the decision-making process preceding the most important end-of-life decision, i.e. the involvement of the patient, patient's family and other healthcare professionals in the decision-making. A final section of the questionnaire asked whether the physician had also deeply sedated the patient until death by use of one or more drugs, and if so the drugs used, the duration of sedation, the administration of artificial nutrition or hydration during the sedation, involvement of patient and family in the decision-making, possible alternatives to sedation, and the physician's life-shortening intention in performing sedation. In the same section questions were asked about opioid use in the last 24 h before death (e.g. dose course).

An overview of all questions, including a complete version of the questionnaire, and the operationalizations derived from the questions can be found in a paper detailing and discussing the methodology of the studies presented here (Chambaere et al., 2008). From the linked death certificate information, data on the patient's sex, exact age, place of death (home, care home, hospital, or other) and underlying cause of death were available. The underlying cause of death variable was coded according to the

International Classification of Diseases, 10th revision based on the combination of causes of death indicated by the certifying physician on the death certificate.

2.3. Statistical analysis

The obtained sample was corrected for the disproportionate stratification procedure (Flanders) and adjusted to be representative for all deaths in 2007 (Flanders and Brussels) concerning age, sex, province, place, and cause of death. Differences between Brussels and Flanders were tested with Pearson χ^2 and Monte Carlo exact tests, with statistical significance set at $p < 0.05$. All statistical analyses were done using SPSS version 17.0.

3. Results

Of the 1961 cases in Brussels and the 6244 in non-metropolitan Flanders, respectively, 701 and 3317 completed questionnaires were returned (Table 1). From the non-response analyses we found response was impossible for 261 deaths in Brussels and 630 in Flanders because the physician was deceased, or because the certifying physician was not the attending physician, did not know the attending physician and had no access to the medical file, or because the physician never received

Table 1

Characteristics of the study samples in Brussels and non-metropolitan Flanders, 2007^a.

	Brussels	Non-metropolitan flanders	p-values ^b
Deaths in study sample	1700	5614	
Response percentage	41.3	59.1	
No. of studied deaths	701	3317	
Age (years)			
1 to 64	22.6	17.2	0.001
65–79	25.6	33.4	< 0.001
80 and older	51.8	49.4	0.246
Sex			
Female	50.2	49.8	0.850
Living situation			
Living alone	37.3	16.3	< 0.001
Living in household with others	43.0	57.2	< 0.001
Living in institution	19.4	26.1	< 0.001
other	0.3	0.3	1.000
Nationality			
Non-Belgian	10.1	2.6	< 0.001
Cause of death			
Cardiovascular disease (excl. stroke)	24.4	26.1	0.348
Stroke	7.3	8.0	0.530
Malignant disease	28.4	27.6	0.666
Respiratory disease	9.4	12.1	0.042
Disease of the nervous system	5.0	3.6	0.078
Other disease	25.5	22.6	0.096
Place of death			
At home	16.0	25.2	< 0.001
In hospital	61.9	49.8	< 0.001
In nursing home	21.0	23.0	0.248
Other	1.1	2.0	0.107
Specialty of attending physician			
GP	34.5	43.5	< 0.001
Clinical specialist	57.1	50.3	0.001
Other	8.4	6.2	0.029

^a Weighted percentages.

^b Tested with Fisher exact test (Monte Carlo).

the questionnaire. As such the response rate was 41.3% for Brussels (701/1700 eligible cases) and 59.1% for non-metropolitan Flanders (3317/5614 eligible cases). The sample sizes compared to total annual deaths are similar in both regions ($\pm 7\%$). Reasons for non-participation as identified by the non-response survey are presented in Table 2.

Compared to the Flemish sample, decedents in Brussels were more often younger than 65 and less often between 65 and 79, significantly more often lived alone and less often in a household with others or in an institution, and were significantly more often of foreign nationality (Table 1). No major differences were found for cause of death: around 28% died of cancer, 24–26% of cardiovascular diseases, 9–12% of respiratory diseases, 7–8% of stroke, and 4–5% of diseases of the nervous system. Decedents in Brussels were less often found to have died at home (16.0% vs. 25.2%) and more often in hospital (61.9% vs. 49.8%) than those in non-metropolitan Flanders.

3.1. End-of-life decisions

Medical end-of-life decisions which possibly shortened life occurred in 38.5% of all deaths in Brussels compared with 47.8% in non-metropolitan Flanders (Table 3). In 20.8% of deaths in Brussels and 20.7% in non-metropolitan Flanders such decisions were possible (i.e. death was anticipated), but were not made.

Table 2

Reasons for non-participation to the survey as identified by the non-response survey, 2007.

	Brussels	Non-metropolitan flanders
Number of answers to the non-response survey	252	954
	%	%
Patient not identifiable by provided data	17.1	23.1
No access to medical file	23.8	13.6
Not treating physician, and not known	30.2	6.7
Not treating physician, but known	11.1	7.7
Physician has principle objections	0.8	9.0
Questionnaire never received or lost	4.4	5.0
No time	2.0	25.2
Physician did not sign certificate	1.6	0.2
Other reason indicated	9.1	9.5

Table 3

Medical end-of-life decisions in Brussels ($N=701$) and non-metropolitan Flanders ($n=3317$) in 2007.

	Brussels $n=701$	Non-metropolitan flanders $n=3317$	p -value ^a
Sudden death (no ELD possible)	40.7	31.6	< 0.001
Non-sudden death, no ELD made	20.8	20.7	0.838
ELD made	38.5	47.8	< 0.001
Intensified alleviation of pain and symptoms	20.4	27.0	< 0.001
Taking into account possible life-shortening	17.7	23.6	0.001
Co-intending life-shortening	2.7	3.4	0.356
Withholding or withdrawing life-prolonging treatment	12.7	17.6	0.002
Taking into account possible life-shortening	4.7	7.3	0.017
Explicitly intending life-shortening	8.0	10.3	0.07
Physician-assisted death, i.e. use of life-ending drugs	5.4	3.2	0.005
On explicit request of patient = euthanasia (including physician assisted suicide)	1.1	1.7	0.325
Without explicit request of patient	4.3	1.5	< 0.001

^a Tested with Fisher exact test (Monte Carlo).

Slightly more than half of those deaths without a preceding end-of-life decision in Brussels and 61% in non-metropolitan Flanders involved comfort care in the last week of life, 43% in Brussels versus 39% in non-metropolitan Flanders involved treatments primarily aimed at cure or life-prolongation (not shown in table).

In Brussels, in 5.4% of cases death was the result of the use of lethal drugs with an explicit intention to hasten death, which was more than in non-metropolitan Flanders (3.2%). In 1.1% of all deaths in Brussels this occurred at the explicit request of the patient (euthanasia) and in 4.3% without an explicit request, which is significantly more than the 1.5% in non-metropolitan Flanders.

Possibly life-shortening intensified pain and symptom alleviation was the most important end-of-life decision in 20.4% (Brussels) and 27.0% (non-metropolitan Flanders) of all deaths. In 17.7% and 23.6% of all deaths in Brussels and non-metropolitan Flanders, respectively, a life-shortening effect of the pain and symptom alleviation was not intended but merely taken into account by the physician. Non-treatment decisions occurred more often as most important end-of-life decision in non-metropolitan Flanders (17.6%) than in Brussels (12.7%). The majority of these decisions were with an explicit intention of hastening death.

Treatment in the last week of life of all non-sudden deaths together was more often primarily aimed at cure or life-prolongation in Brussels than in non-metropolitan Flanders (31% vs. 22% of non-sudden deaths) (not in table).

3.2. End-of-life decisions according to characteristics of the dying person

Compared with non-metropolitan Flanders, in Brussels euthanasia tended to occur more frequently in people aged 80 or older and significantly less often in those aged 1–64 and in those with cancer (Table 4). Whereas the incidence of euthanasia in non-metropolitan Flanders was notably higher at home, this was not the case in Brussels. As compared with non-metropolitan Flanders, life-ending without an explicit request occurred in Brussels relatively often in people 1–64 years, in those living alone and in those living (and dying) in a care home, and in persons dying from respiratory or neurodegenerative diseases. The incidence of possibly life-shortening pain and symptom alleviation in Brussels was relatively low at home (13.4%) and in care homes (17.0%). In particular in hospitals and in those suffering from respiratory diseases, the incidence of non-treatment decisions was lower in Brussels than in non-metropolitan Flanders.

Table 4Medical end-of-life decisions in Brussels ($n=701$) and non-metropolitan Flanders ($n=3317$) according to patient characteristics, 2007.

	Euthanasia (incl. PAS)		Life-ending without explicit request		Intensified symptom alleviation		Non-treatment decision	
	BRU ^a	FLA ^a	BRU ^a	FLA ^a	BRU ^a	FLA ^a	BRU ^a	FLA ^a
Total	1.1	1.7	4.3	1.5	20.4	27.0	12.7	17.6
Sex								
Men	1.1	2.1	4.0	1.4	18.4	27.2	13.2	14.6
Women	1.1	1.3	4.6	1.6	22.6	26.8	11.7	20.5
Age								
1 to 64	0.0	4.0	5.1	0.9	18.9	28.8	10.8	14.2
65–79	1.1	2.1	2.8	2.3	24.2	27.4	13.4	17.6
80 and older	1.7	0.6	4.7	1.2	19.3	26.1	12.7	18.7
Living situation								
Living alone	0.8	1.3	5.0	0.6	18.2	26.2	11.6	17.4
Living in household with others	1.0	2.3	3.4	1.9	20.8	28.1	12.5	16.9
Living in institution	2.2	0.6	5.3	0.9	22.6	25.4	15.0	19.5
other	0.0	0.0	0.0	0.0	50.0	33.3	0.0	30.0
Place of death								
At home	0.9	3.7	0.9	1.3	13.4	29.4	8.0	7.9
In hospital	1.4	1.3	4.8	1.8	24.0	25.7	13.2	22.0
In nursing home	1.4	0.5	5.4	1.0	17.0	28.6	15.0	19.9
Other	0.0	0.0	0.0	0.0	0.0	9.2	0.0	0.0
Cause of death								
Cardiovascular disease (excl. stroke)	0.0	0.3	3.5	0.6	12.2	17.3	10.5	16.5
Stroke	2.0	0.0	5.9	3.4	19.6	17.0	15.7	22.3
Malignant disease	1.5	4.8	2.5	2.1	37.7	46.2	13.1	13.8
Respiratory disease	1.5	0.8	6.2	1.3	16.9	19.6	10.8	22.9
Disease of the nervous system	2.9	3.4	11.4	1.7	13.9	31.9	22.2	20.2
Other disease	1.1	0.4	4.5	1.2	12.3	21.6	11.7	18.5

Bold and underlined: $p < 0.05$ (Fisher exact, Monte Carlo procedure).^a BRU=Brussels, FLA=non-metropolitan Flanders.

3.3. Decision-making process

The process preceding the different end-of-life decisions in Brussels was very similar to that in non-metropolitan Flanders, except for intensified pain and symptom alleviation, which was discussed less often with relatives or palliative care specialists in Brussels but more often with other physicians (Table 5). Euthanasia was by definition always discussed with the patient (albeit in one instance in the form of a living will), and in most cases with the family and with another physician. Life-ending without an explicit patient request implies that the decision had not been made at the explicit request of the patient, but it had often been discussed with them previously, or a previously stated wish had been made at some point. In 38.8% of cases (Brussels) and 21.0% (non-metropolitan Flanders) no discussion occurred but the dying person was no longer competent.

In cases of hospital deaths, intensified pain, and symptom alleviation had less often been discussed with the decedent in Brussels than in non-metropolitan Flanders (not in table).

3.4. Continuous deep sedation until death

Of all deaths in Brussels 14.3% involved continuous sedation until death, which is comparable to the incidence of 13.9% found in non-metropolitan Flanders (Table 6). In 60.8% of these cases in Brussels the dying person was sedated by means of benzodiazepines, in 29.4% only opioids were used. For 16.2% of all sedated cases in Brussels, the sedation lasted more than a week, which is significantly more than the 8.3% in non-metropolitan Flanders. In 60.4% of cases in Brussels sedation was combined with administration of artificial nutrition and hydration until death, as compared to 40.9% in non-metropolitan Flanders. In Brussels, a significantly higher proportion of sedation cases occurred without a request by or

consent from patient or family than in non-metropolitan Flanders (29.9% vs. 19.5%).

Compared with non-metropolitan Flanders the incidence of continuous deep sedation until death in those dying at home was significantly lower in Brussels (10.1% vs. 3.5%) (not in table).

4. Discussion

This study aimed to examine the characteristics and incidence of various end-of-life decisions in the Brussels metropolitan region and to explore whether there are significant differences with the non-metropolitan Flanders region. In 1.1% of all deaths in the metropolitan region of Brussels lethal drugs were administered at the explicit request of the dying person (i.e. euthanasia), while in 4.3% life-ending drugs were administered without an explicit request from them. A fifth of all deaths were preceded by possibly life-shortening intensification of pain and symptom management, and 12.6% by a possibly life-shortening non-treatment decision. In 14.3% of cases, the dying person was continuously and deeply sedated until death. Compared to the non-metropolitan region of Flanders the incidence of most end-of-life decisions was lower except for the use of life-ending without explicit patient request, which was higher. A lower incidence of intensified pain and symptom alleviation and of continuous deep sedation was found particularly among those dying at home in Brussels, and continuous deep sedation was performed more often in Brussels than in Flanders without a request or consent from the dying person or their family.

This study is the first to examine the incidence and characteristics of end-of-life decisions in the Brussels metropolitan region, as previous studies in Belgium have been limited to Flanders. The robust study design and validated questionnaire, used in previous studies, strengthen the validity and reliability of

Table 5

Decision-making process preceding medical end-of-life decisions in Brussels and non-metropolitan Flanders, 2007.

	Euthanasia (incl. PAS)		Life-ending without explicit request		Intensified symptom alleviation		Non-treatment decision	
	BRU ^a	FLA ^a	BRU ^a	FLA ^a	BRU ^a	FLA ^a	BRU ^a	FLA ^a
Unweighted number of cases	8	112	29	57	139	1171	88	524
Discussion with patient								
Discussed	87.5	100	18.4	22.1	22.1	23.1	33.4	20.1
Not discussed but previous living will or expressed wish	12.5	0.0	38.8	21.0	19.4	14.6	15.5	20.4
Not discussed, no living will or expressed wish, patient no longer competent	0.0	0.0	42.8	54.1	48.9	52.0	48.1	56.3
Not discussed, no living will or wish, and patient competent	0.0	0.0	0.0	2.8	9.6	10.3	3.1	3.2
Discussion with relatives or close ones								
Discussed	87.5	77.2	82.8	79.6	50.4	66.4	71.6	69.7
Discussion with other professional caregivers								
Physician and palliative care specialist	38.0	47.5	15.5	8.5	11.2	14.7	12.6	12.4
Physician, no palliative care specialist	51.8	29.4	53.3	43.4	41.6	26.5	53.3	42.1
Palliative care specialist (not physician)	0.0	3.0	2.8	1.6	3.0	7.9	6.5	3.6
Nurse only	10.1	1.3	17.7	1.9	1.4	3.4	1.1	1.7
No other professionals	0.0	6.8	10.7	9.7	11.6	12.0	14.3	13

Bold and underlined: $p < 0.05$ (Fisher exact, Monte Carlo procedure)^a BRU=Brussels, FLA=non-metropolitan Flanders.**Table 6**

Incidence and characteristics of continuous deep sedation until death in Brussels and non-metropolitan Flanders, 2007.

	Brussels	Non-metropolitan Flanders
Weighted incidence (unweighted number of cases)	14.3 (95)	13.9 (501)
Drugs used		
Only benzodiazepines	7.8	10.9
Benzodiazepines and opioids	50.9	45.3
Benzodiazepines and other drugs	2.1	1.1
Only opioids	29.4	29.9
Opioids and other drugs	5.4	7.3
Only other drugs	4.5	5.5
Time before death initiated		
0–48 hours	43.2	41.0
2–7 days	40.6	50.9
> 1 week	16.2	8.3
Artificial food and fluid		
Administered until death	60.4	40.9
Administration discontinued during sedation	21.8	9.2
Not administered	17.8	49.9
Request or consent		
Request by patient	5.6	9.1
No request, but consent from patient	18.4	20.2
No request or consent from patient, but request by family	11.7	11.2
No request or consent from patient, but consent from family	34.3	39.9
No request or consent from patient or family	29.9	19.5
Life-shortening intention		
None	35.8	33.0
Possible life shortening taken into account	46.0	52.0
Life shortening co-intended	15.6	12.5
Life shortening explicitly intended	2.6	2.5
Clinical alternatives (according to physician)		
None	78.2	81.3
Symptom control without deep sedation	6.5	5.6
Only life-ending acts	10.9	11.1
Other	4.4	2.1

Bold and underlined: $p < 0.05$ (Fisher exact, Monte Carlo procedure).

both the results for Brussels and the comparison with non-metropolitan Flanders. Whereas the response rate was satisfactory for non-metropolitan Flanders, that for Brussels was rather low, increasing the risk of non-response bias. However, response and non-response differed only slightly in terms of decedent

characteristics relating to place of death and not at all in terms of age, sex, cause of death, marital status, or educational attainment. Comparison of the non-response surveys in Brussels and Flanders showed that the lower response for Brussels might be typical of the metropolitan situation, with more physicians not

remembering the deceased patient due to short-lived/transitory contacts, or no longer having access to the patient file because they no longer worked in the same hospital. A non-response survey among physicians from four European countries being surveyed about their attitudes and experiences regarding end-of-life decisions in 2002 found that non-response did not cause socio-demographic distortion, but non-responders had statistically significantly lower agreement rates when asked about their acceptance of euthanasia in Denmark, Sweden, and Switzerland, but not in the Netherlands (Fischer et al., 2006). Response bias in the reported behavior in the current study is thus possible. An important limitation inherent in the research methodology used is that our study only provides information from the physician's perspective and is not designed to determine causal inferences. Additionally, the reliance on physicians reporting their own practices makes the estimation of incidence of end-of-life decisions sensitive to their a posteriori perception of their actions. A growing amount of research shows that, contrary to the beliefs of physicians, opiates rarely hasten death and, hence, they tend to believe wrongly that the administration of opiates may hasten death (George and Regnard, 2007; Sykes and Thorns, 2003), and consequently account for it in their decision-making. This is an important conclusion that should be taken into consideration particularly when interpreting the relatively high frequency of possibly life-shortening pain and symptom alleviation. A recent study in the UK, using a similar questionnaire but with a rewording of the questions regarding this practice (i.e. 'taking into account a possible life shortening effect' was reformulated as 'knowing this would probably or certainly hasten the end of life') has indicated that a different formulation of the question can lead to a lower incidence estimate (Seale, 2009). This has implications for incidence figures in both Brussels and Flanders, but not so much for the comparison between them.

Overall, fewer end-of-life decisions were made in Brussels compared with non-metropolitan Flanders and, apart from the use of lethal drugs, all end-of-life decisions occurred less often in Brussels than in Flanders. Accordingly, treatment in the last week of life of those not dying suddenly or unexpectedly was more often aimed at cure or life-prolongation in Brussels than in non-metropolitan Flanders. Also, fewer palliative care specialists were consulted regarding end-of-life decisions, and more deaths occurred in hospital than at home or in care homes. This may all point to a tendency towards more aggressiveness of care in the Brussels metropolitan region, and is consistent with the urban–rural differences in aggressiveness of care found in studies in the USA (Gessert et al., 2006a, 2006b; Gessert and Calkins, 2001).

A useful model to explain the metropolitan vs non-metropolitan differences observed and the different ways in which the metropolitan environment can influence end-of-life decisions is the conceptual framework for urban health developed by Galea et al. (2005). In this framework, population health is influenced by the urban environment in its broadest sense (physical, social, economic, and political), i.e. by characteristics of the urban population, municipal level determinants and major trends such as immigration and globalization.

First, end-of-life decisions in a metropolitan population can be influenced by characteristics of the urban population: demographic (i.e. population composition), the social environment (i.e. social networks and social support), and the physical environment (i.e. housing) of the metropolitan area. Demographic characteristics could for instance explain why euthanasia in metropolitan Brussels was not predominantly limited to the 'typical' patients (i.e. cancer patients, patients younger than 64, and those dying at home), and why using lethal drugs without explicit patient request occurred more often in younger people in Brussels compared with non-metropolitan Flanders (Bilsen et al.,

2009) and other countries (van der Heide et al., 2003, 2007). Older people dying in Brussels are relatively more highly educated and younger people relatively less highly educated than their Flemish counterparts (Deboosere et al., 2009). Euthanasia has been demonstrated to be accepted and valued more by more highly educated people (Cohen et al., 2006). It can also be hypothesized that as younger people dying in Brussels more often have a migrant background, they may more often have cultural or religious reservations (Burdette et al., 2005; Caralis et al., 1993; Cohen et al., 2006; Larue, 1985; Sachedina, 2005) which make communication on the subject difficult.

The social environment of the metropolitan area also influences end-of-life decisions: the social fragmentation of the metropolitan area was expected to trigger a lower involvement of family in end-of-life decision-making, as proved to be the case in relation to intensified pain and symptom alleviation where relatives were involved in 50% of cases as opposed to 66% in non-metropolitan Flanders. Lower levels of social support and fewer social networks, as well as weaker relationships with GPs in the metropolitan area, have also been identified in previous studies as reasons for fewer people receiving end-of-life care in their own home (Houttekier et al., 2009, 2010). These studies refer to fewer families in Brussels having a GP (16% points difference) and fewer contacts if they do have one, as reasons for reduced access to good end-of-life care and greater use of hospitals for care. Lower levels of social support, illustrated by the fact that 37% of dying people in Brussels in our study were single compared to 17% of those in non-metropolitan Flanders, are also likely to result in less end-of-life care at home. As a possible consequence of this, the percentage of patients dying in hospital in Brussels (62%) was considerably higher than in non-metropolitan Flanders (50%). Lack of social support and hence the reduced ability to manage care in the home, could also explain why several end-of-life decisions (e.g. euthanasia, intensified pain and symptom alleviation, continuous sedation until death) occurred relatively infrequently at home in Brussels as compared with non-metropolitan Flanders.

Environmental factors such as housing which is less hospitable to end-of-life care and apartment blocks with stairs, likewise affect numbers of home deaths; thus, as the setting has been demonstrated to influence end-of-life decision-making (Cohen et al., 2007), both the social and physical environment of the metropolitan area indirectly influence the end-of-life decision-making.

Second, municipal level determinants will influence end-of-life decisions, indirectly e.g. through the state of the housing market affecting housing conditions, and through the level of social support and availability of social networks determined by civil society. But there can also be a direct influence through community-based organizations providing or negotiating certain health care services. One of the problems for metropolitan areas such as Brussels is that socially fragmented communities often do not 'speak each other's language', which complicates coordinated and united actions or advocacy, e.g. for home care, hospice care, or informal care networks. In addition to there being communities from different origins, the official bi-communal (i.e. Flemish and French-speaking community) health care policy in Brussels probably complicates federal and civil initiatives even further. Whilst national policies attempt to relocate end-of-life care from the institutional to the domestic, this lack of common action and advocacy undermines these policies and may impede the shift towards provision of formal and informal care support within the home (Milligan, 2000). This could contribute to explaining the relatively low proportion of home deaths and of intensified pain and symptom alleviation and continuous sedation until death performed at home in Brussels. There may, nonetheless, be an unmet need in the Brussels metropolitan area for more accessible palliative care at home or in hospices, which could contribute to

less aggressive care and to more adequate end-of-life care in the home situation, which could in turn stimulate the timely elicitation of end-of-life care preferences and the discussion of end-of-life decisions (Cohen et al., 2007), as well as improving the overall dying experience (Yao et al., 2007).

A third level of factors influencing end-of-life decision-making in the metropolitan environment is that of global and national trends, as well as the implementation of government policies in cities. One of the major global trends defining the metropolitan environment is immigration; immigration is primarily an urban phenomenon and over half the Brussels population is currently of non-Belgian origin (Deboosere et al., 2009). A majority of new immigrants in Brussels are burdened with poverty while language and cultural barriers complicate the delivery of health care. As illustrated above, the larger proportion of non-Belgians dying in Brussels is likely to influence the frequency and socio-demographic patterns of end-of-life decisions and also to cause additional communication problems due to language issues and cultural-attitudinal issues (e.g. differences in the acceptability of end-of-life decisions). Good communication on end-of-life decisions with people from different cultures and with different mother tongues is something that should be addressed in order to anticipate further problems in the future. Another national healthcare policy factor influencing the metropolitan environment is the tendency to concentrate specific types of care in metropolitan areas through large academic hospitals. A larger number of accessible health services are usually assumed to contribute to better health care (Galea et al., 2005). Our study, on the other hand, seems to suggest that the higher availability of services within a metropolitan environment, in particular because of a stronger emphasis on cure in the development of those services (Gessert et al., 2006), can imply a disadvantage in terms of end-of-life care which typically requires a modest and non-heroic attitude of the physician, and communicative equality between patient and physician. Without ignoring the possibility that people in the two regions may in fact have different end-of-life care preferences, the lower availability of adequate palliative care, the more intra-mural organization of end-of-life care, and the weaker relationship with the GP also partly explain the low number of people dying at home in Brussels (Houttekier et al., 2009, 2010). The combination of hospitals numbers being a pull factor towards end-of-life care in hospitals (Houttekier et al., 2010) and a treatment culture which is aimed more at 'heroic' cure of pathologies and less at caring for people within their social context, impacts on the characteristics of end-of-life care. This may also explain the somewhat worrying figure found in our study that 4.3% of all deceased people in Brussels had received lethal drugs without their explicit request, which is notably higher than the 1.5% found in non-metropolitan Flanders. It can be hypothesized that this life-ending without explicit request is often due to a lack of anticipatory discussion about the end-of-life care trajectory. In more than half of cases of life-ending without explicit request in our study the dying person had still received treatment predominantly focused on cure or life-prolongation in the last week. The lack of timely involvement of palliative care services in favor of more heroic treatment, thereby avoiding a discussion that could upset all parties involved, is probably often the reason for this finding. It can be hypothesized that the higher frequency of this practice observed in the Brussels metropolitan region is related to the large concentration of academic hospitals and the less stable relationships with GPs resulting in fewer continuous care trajectories tailored to the individual patient. In a sense it could be stated that this environment of concentration of academic hospitals and fewer and weaker patient-GP ties entails what is referred to as 'distant ethics' (Duff, 1987): a propensity to make decisions based on rules or professional expertise and to

exclude active participation of patients and families. Distant ethics oppose 'close-up ethics' where patient- and family-centered decision-making is a core attribute. The extent to which a patient and his/her family are known by the treating physician will to a large extent influence the type of ethics practiced, distant or close-up. It could be hypothesized that end-of-life decisions are possibly more likely to be patient- and family-centered (i.e. close-up ethics) in non-metropolitan areas than in metropolitan areas, where interactions between patients and clinical specialists are believed to be more cursory. This could also explain our finding that intensified pain and symptom management was discussed significantly less often with the patient in hospitals in the Brussels metropolitan area. It is probably much more regarded as an expertise-based decision in which patient preferences or sentiments need not play a role. That life-ending without explicit patient request in Brussels occurred relatively often in dying people younger than 65 may also be related to the physician's (and in particular specialist's) a priori reluctance to shift a younger patient's treatment from cure to palliation, making timely discussions on euthanasia less likely. The different emphasis of end-of-life care and the different development of end-of-life care services in the metropolitan area are also apparent from our finding that, compared with Flanders, intensified pain and symptom alleviation and continuous deep sedation until death rarely occurred in those dying at home (3.5% vs 10.1% in non-metropolitan Flanders). Even euthanasia was rarely performed at home in Brussels (0.9% of all home deaths vs 3.7% in non-metropolitan Flanders), while it usually tends to occur at home in other regions and countries (Cohen et al., 2007).

5. Conclusion

Our study showed that in a relatively large number of deaths in Brussels lethal drugs are administered, more often without than with an explicit patient request. Decisions to intensify pain and symptom alleviation and non-treatment decisions occur less often than in non-metropolitan Flanders and treatment in the last week of life is more often aimed at cure or life prolongation. We have suggested that several characteristics of the metropolitan environment influence these differences in end-of-life decisions. Characteristics of the metropolitan population (e.g. the greater numbers of people living alone, of people of foreign origin, of more highly educated older people and less highly educated younger people, and the less favorable housing conditions), municipal level determinants (e.g. lack of care support initiatives due to social fragmentation), and major global and national trends (e.g. end-of-life care being more hospitalized and cure-oriented in metropolitan areas) seem to contribute to the differences between end-of-life decision-making in Brussels and in Flanders. It is hypothesized that the notable differences between metropolitan Brussels and non-metropolitan Flanders reflect typical 'metropolitan issues' and may therefore also apply in other metropolitan regions of the world, although research is needed to confirm this. If such is the case, it may be opportune, with a growing number living and dying in metropolitan areas and their increasing influence on the health care of a country, to develop a specific focus on and approach to end-of-life decisions in metropolitan areas, both on a public health level and on the individual level of physicians who work there. It would also seem to be important to develop a public health end-of-life care policy which more fully takes into account aspects of metropolitan geography (Brown, 2009), anticipating problems related to the social and physical environment, and adapting health services to the end-of-life care needs of metropolitan residents.

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Conflict of interest statement

All authors have no conflict of interest to declare.

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